

# NORTH COUNTY PARKINSON'S SUPPORT GROUP

March 2019



NEWSLETTER for Carlsbad, La Costa, Fallbrook, Oceanside, and Rancho Bernardo Support Groups

## PASD "Step-by-Step" 5K Walk - April 7

Parkinson's Association San Diego's (PASD) "Step-by-Step" 5K Walk is an annual "happening" that combines a fun outdoor event, with optional exercise, and information from major Parkinson's organizations – AND is an important fundraiser for PASD's services to people with Parkinson's county-wide.



Talk to anyone who's done the Walk in previous years. It's a great social event in a nice venue – Liberty Station, Point Loma. It's a super event, whether you walk the whole 5K (3 mile) route or take any **or all** of the shortcuts – or you just go for the fun of it.

PASD provides services all across the County, including

- ♦ The **"Good Start Program"** helping recently-diagnosed folks understand the disease, the options for services, and offering hope as scientists move toward a cure,
- ♦ a sponsorship through **FACT – Facilitating Access to Coordinated Transportation** – a non-profit service that coordinates transportation resources for Parkinson's-related events (*including the 5K Walk*) or appointments – offering travel for people with Parkinson's and their care partner for FREE or reduced cost,
- ♦ a **website** with valuable Parkinson's-related resources, and contact information for more than 20 Support Groups in our area – including NCPSPG chapters, helping people locate nearby meetings and activities,
- ♦ **Equipment exchange**, providing mobility equipment for Parkinsonians, available for free, and accepting donated equipment, and
- ♦ **Special programs** like the educational, motivating **"Empowerment Day"**, and partnerships with the Davis Phinney Foundation's **"Sidekicks"** linking Parkinsonians with youth through art.

We encourage you to join our NCPSPG Team on the Walk, or form your own team under our banner, and to encourage family & friends to donate.

Three great ways to build a team, update friends and family of your journey, and raise money for PASD:

- ◇ via the PASD website: [www.ParkinsonsAssociation.org](http://www.ParkinsonsAssociation.org)
- ◇ via your **Facebook** page or other social media
- ◇ sending a **personal letter** to family and friends – especially when you include a self-addressed return envelope.

You will be pleasantly surprised by the response of friends and family, and you'll be empowered by the opportunity to tell them of your attitude and approach to PD, such as *"I may have Parkinson's, but Parkinson's doesn't define me."* You'll be helping them understand your challenges, showing you're open to discussing PD, and helping them to be part of the solution. What a wonderful opportunity!

### Inside This Issue

- **Events Calendar** Page 2
- **In Focus: Exercise Options** Page 3
- **List of Parkinson's research opportunities in San Diego County** Page 4

**UC San Diego Health presents: *Parkinson Outside the Box*** a free event

**Saturday March 16 9:30am to 4pm** Irwin M Jacobs Qualcomm Hall 5775 Morehouse Dr, SD 92121  
Broad range of topics - for people with Parkinson's and care partners. Refreshments and light lunch provided.  
Registration is required by March 8: [health.ucsd.edu/parkinsonsevent](http://health.ucsd.edu/parkinsonsevent) Questions? 619 543-2445

## Support Group Meetings

### **RANCHO BERNARDO - Monday, March 4<sup>th</sup>**

**10 am - noon (NCPGS Sponsored)** (first Monday of each month,) San Rafael Catholic Church, 17252 Bernardo Center Drive, San Diego (RB)

Speaker: **Matthew Ignacio**, Tremble Clefs leader

Subject: **Voice Exercises and Singing Therapy** for the Parkinson's Community. Breakouts follow where people with Parkinson's and care partners meet separately to discuss issues and successes. Refreshments. Call **Britt King 858-354-2498**.

### **LA COSTA CARLSBAD - Wednesday March 6<sup>th</sup>**

**1pm - 3 pm (NCPGS Sponsored)** (first Wednesday of each month) Christ Presbyterian Church, 7807 Centella St, Carlsbad, CA 92009

Speaker: **Pat McDonnell** of Medtronics

Subject: **Deep Brain Stimulation** for the motor symptoms of PD. Breakout groups follow. Call **Rex McCoy 760-519-9588**.

### **OCEANSIDE - Wednesday, March 13<sup>th</sup> (NCPGS Sponsored)**

**1pm - 3pm** (second Wednesday of each month) at **Oceanside First Presbyterian Church** 2001 S. El Camino Real, Oceanside.

Speaker: **Marty Acevedo** - Ambassador for Davis Phinney Foundation.

Subject: **"Sidekicks"** Youth and Art Combine for PD. Breakout groups follow. Call **Paul Dawson 760-497-1200**.

### **FALLBROOK - Friday, March 22<sup>nd</sup> 10 am - noon**

**(NCPGS Sponsored)** (meets fourth Friday of each month) at **Christ The King Lutheran Church**, 1620 S. Stage Coach Lane, Fallbrook.

Speaker: **Jeani Grosbeck & Jon Ezzo** - Care Choice Home Care

Topic: **Recognizing when I need Help** and How to Select an In-Home Care Agency. Followed by a time for sharing included for PWP & Care Partners. Refreshments served.

Call **Irene Miller 760-731-0171**

### **ATYPICAL Parkinson's (Caregivers only)**

**Wednesday, March 4<sup>th</sup> 11am - 1pm**

(first Wednesday of every other month) at Tri-City Wellness Center, 6250 El Camino Real, Carlsbad.

Contact **Darlene Gerow 619-806-9649**

[darlene.gerow@gmail.com](mailto:darlene.gerow@gmail.com)

### **ATYPICAL Parkinson's (PwP & Caregivers)**

**Monday, March 18<sup>th</sup> 1pm - 3pm** (third Monday of the month) at UCSD, East Campus, 9423 Health

Science Drive, Medical Center Modular 1, Room 140, La Jolla. Contact **Darlene Gerow 619-806-9649**

[darlene.gerow@gmail.com](mailto:darlene.gerow@gmail.com)

## Physical Exercise

### **CARDIFF LOCATION - Tuesdays & Thursdays**

**11am - noon (NCPGS Sponsored)** Encinitas Elks Lodge, 1393 Windsor Rd., Cardiff. Take I-5 to Santa Fe exit east to Windsor Rd. and turn right. (Fee charged). Call **Betty Byrd 760-635-1144**.

### **OCEANSIDE LOCATION - Fridays 11am - Noon**

Tri-City Hospital, 4002 Vista Way, Oceanside, Lower level Assembly Room, (Free) Confirm room location at lobby info desk. Valet parking available. Call **Tracy Park, PT, 760-940-3617**.

### **DANCE FOR PARKINSON'S (Encinitas class)**

**Suspended until further notice** Although our Thursday program in Encinitas has been suspended, *Dance for Parkinson's* is being presented by **Cheryl McIlhon** at Tri-City Wellness/Fitness Center. See the following...

### **MEDICAL INTEGRATED PROGRAM - Mondays & Wednesdays, or Tuesdays & Thursdays**

Tri-City Wellness & Fitness Center, 6250 El Camino Real, Carlsbad. Parkinson's exercise classes (Fee charged.) Call **Susan Webster 760-931-3171**.

### **PERSONALLY FIT - Tuesdays & Thursdays 2pm - 3pm**

Parkinson's exercise classes at Personally Fit in Rancho Bernardo. (Fee charged.) Call **858-485-6706**

## Vocal Exercise

**Tremble Clefs** -Therapeutic Singing **Tuesdays 1pm - 2:30pm** St. Andrews Episcopal Church, 890 Balour Dr., Encinitas. New members always welcome. (Free) Call **Deanna Hastings at 619-363-0814** or check website: [www.trembleclefs.com/san-diego](http://www.trembleclefs.com/san-diego)

**AudAbility** - This music therapy program offers numerous music related activities for People with Parkinson's. (Fee charged) For more information, call **Lindsay Zehren at 858-457-2201** or email [lzehren@musicworxinc.com](mailto:lzehren@musicworxinc.com).

## Small Social Groups

Our small social groups gather in rotating private homes on the third Monday of each month that we don't have a large group activity. Come and join us in Oceanside or Rancho Bernardo in a safe environment where we all understand and support each other. Contact **Sam Cooper**, Social Chair, [scprphd@gmail.com](mailto:scprphd@gmail.com) or call/text **520-820-0339**.

## NCPGS Board of Directors

**Wednesday March 20<sup>th</sup> 1pm - 3pm**

Tri-City Wellness Center, large conference room, 6250 El Camino Real, Carlsbad. Contact **Paul Dawson 760-497-1200** [paul@video-fire.com](mailto:paul@video-fire.com)

**Christ Presbyterian Church La Costa, Oceanside First Presbyterian Church, Christ the King Lutheran Church Fallbrook, and San Rafael Catholic Church, RB provide their facilities at no charge. Thank You!**

## In Focus: How We Exercise

By Sam Cooper



Our "In Focus" interview is a little different this month. We all know exercise is good for everybody. It is particularly good for Parkinson's. Our North County mantra is always "Exercise! Socialize!", but what exactly does exercise look like? Here are some of our folks and how they are using what kind of exercise to improve their daily lives. Many people participate in more than one program.

**Tri-City Hospital Exercise:** Under the leadership of physical therapist **Tracy Park**, Tri-City Hospital offers an exercise program specifically designed for Parkinson's. **Jim and Miriam Campbell, Sam and Georgia Lazar, Stephen and Stephanie Lester, and Phil and Nelly Souther** are among the regular attendees.

**Cycling:** **Art Bierle** rides his three wheel bicycle several times a week with friends often covering 25 miles at a time. He folds the bicycle for transport in his SUV.

**Encinitas Elks Lodge:** Coordinated by past Board treasurer **Betty Byrd**, the Encinitas Elks Lodge hosts a Parkinson's-focused exercise program. Participants include **Lawrence and Joy Rogers, and Robert and Marianne Leard**.

**Rock Steady Boxing:** According to participant **Howard Maher**, "Boxing offers all the exercises - stretching, strength, and weight maintenance". Other participants include **Frank Finn, Bill Shinner, Dean Hluchn, Gene Burns, Ron Miller, Pete Miller, and Frank Hainey**.



**Tri-City Wellness Fitness Center:** The Wellness Center offers a medically integrated exercise program for Parkinson's. **Otto Probst, Gary Larson, Russ and Judy Reed, Eiko Roberts, and Frank Finn** take advantage of this opportunity.

**Yoga:** Yoga just isn't about stretching. It also offers strength and balance opportunities. Just ask La Costa co-leader **Eva Zamora** about its many benefits.

**AudAbility:** A researched brain based music therapy program, AudAbility helps People With Parkinson's improve vocal production and breathing. **Ken King** uses the harmonica.



**Tremble Clefs:** A vibrant performing group, Tremble Clefs offers voice therapy and mutual social support through singing. **Teresa Ruelas, Madonna Bingham, Robert and Carol DeLillo, Hillary Jacobson, and Bud Nelson** enjoy the group immensely.

**Square dancing:** Just when you thought dancing was only about fun. **Jim and Margaret Girkin** wouldn't ask why you should get exercise by square dancing, they would ask why not get exercise by square dancing? Swing your partner!

**Walking:** Walking is something virtually everyone can do virtually anywhere and here in our beautiful SoCal, North County locations to walk seem endless from the beach to your neighborhood to Mt. Calevera which **Les and Betty LaPlante** hike frequently and invite anyone who is interested to join them. Other walkers include **Ron and Sandy Miller, Rick and Linda Ankrom, and Marty Acevedo**.

**Swimming:** Its great all-around exercise that accommodates balance issues well. **Ken King** and others jump into the pool several times a week - and one member we know goes ocean swimming on a regular basis!

**Boxing to exercise classes, singing to walking.  
It doesn't matter HOW you move, it matters THAT you move.  
Just do it! You'll feel better. You'll do better!**

---

Exercise with us on **April 7** at the **PASD 5K Walk - Liberty Station** **Join our NCPSPG Team!**

## CONTACTS

### Rancho Bernardo Support Group Co- Leaders

Carol Maher [hcmaher@cox.net](mailto:hcmaher@cox.net)  
760-749-8234

Brigit King [icedancer@san.rr.com](mailto:icedancer@san.rr.com)  
858-354-2498

### La Costa Support Group Leader

Rex McCoy [rmcco@cox.net](mailto:rmcco@cox.net)  
NCPSP Board Vice President 760-519-9588

### La Costa Co-Leader

Eva Zamora [3evazamora@gmail.com](mailto:3evazamora@gmail.com)  
760-814-3479

### Oceanside Support Group Leader

Paul Dawson [paul@video-fire.com](mailto:paul@video-fire.com)  
NCPSP Board President 760-497-1200

### Oceanside Co-Leader

Madonna Bingham [granny6mb@gmail.com](mailto:granny6mb@gmail.com)  
760-757-7564

### Fallbrook Support Group Leader

Irene Miller [imiller4jc@gmail.com](mailto:imiller4jc@gmail.com)  
760-731-0171

### Fallbrook Support Co-Group Leader

(vacant)

### Treasurer, Recording Secretary & Webmaster

Caryl Parrish [cparrish@prodigy.net](mailto:cparrish@prodigy.net)  
760-753-5004

### Corresponding Secretary

Micheline Allen [micheline.allen@cox.net](mailto:micheline.allen@cox.net)  
760-631-0649

### Parkinson's Association Liaison

Thelma Balbes (PA Board member) 760-918-9887

### Social Director

Sam Cooper [scprphd@gmail.com](mailto:scprphd@gmail.com)  
520-820-0339

### Video Documentation

Arthur Bierle [Google: Arthur Bierle on Vimeo](https://www.youtube.com/watch?v=Google: Arthur Bierle on Vimeo)  
760 749-2182

### Library

Madonna Bingham [granny6mb@gmail.com](mailto:granny6mb@gmail.com)  
760-757-7564

### Newsletter

**Publisher** [paul@video-fire.com](mailto:paul@video-fire.com)  
Paul Dawson 760-497-1200

### Focus Interviews

Sam Cooper [scprphd@gmail.com](mailto:scprphd@gmail.com)  
520-820-0339

### Printed Edition Distribution

Madonna Bingham [granny6mb@gmail.com](mailto:granny6mb@gmail.com)  
760-757-7564

### Electronic Distribution

[micheline.allen@cox.net](mailto:micheline.allen@cox.net)

## Passings

- ◆ Kie Ho
- ◆ Roger Hiniker
- ◆ Joan Coffey

Thoughts and prayers to families & friends

**Parkinson's Disease Studies in San Diego County Area** - currently recruiting participants  
See the full spreadsheet on the [NCPSPG.org](http://NCPSPG.org) website.

Title	Interventions	Sponsor/Collaborators	Phases	Study Type	Locations	URL
Effects of Osteopathic Manipulative Treatment (OMT) on Gait Biomechanics in Parkinson's Disease	Procedure: Osteopathic Manipulative Treatment (OMT)   Other: Light Touch	University of California, San Diego	Not Appl	Intervention	University of California, San Diego, La Jolla, California, United States	<a href="https://clinicaltrials.gov/show/NCT03616145">https://clinicaltrials.gov/show/NCT03616145</a>
Cognitive Rehabilitation for PD-MCI	Behavioral: CogSMART-PD   Behavioral: Supportive Care	VA Office of Research and Development	Not Appl	Intervention	United States	<a href="https://clinicaltrials.gov/show/NCT03351510">https://clinicaltrials.gov/show/NCT03351510</a>
The Parkinson's Genetic Research Study		University of Washington	Observation	Observation	La Jolla, California, United States	<a href="https://clinicaltrials.gov/show/NCT0358479">https://clinicaltrials.gov/show/NCT0358479</a>
A Global Study to Assess the Drug Dynamics, Efficacy, and Safety of GZ/SAR402671 in Parkinson's Disease Patients Carrying a Glucocerebrosidase (GBA) Gene Mutation	Drug: GZ/SAR402671   Drug: Placebo	Genzyme, a Sanofi company   Sanofi	Phase 2	Intervention	Investigational Site Number 840004, La Jolla, California, United States	<a href="https://clinicaltrials.gov/show/NCT02906020">https://clinicaltrials.gov/show/NCT02906020</a>
Study to Identify Clinical, Imaging and Biologic Markers of Parkinson Disease Progression	Drug: Datscan and AV-133	Ken Marek, MD   Institute for Neurodegenerative Disorders   Michael J. Fox Foundation for Parkinson's Research	Phase 2	Intervention	University of California San Diego, La Jolla, California	<a href="https://clinicaltrials.gov/show/NCT01141023">https://clinicaltrials.gov/show/NCT01141023</a>
Evaluating the Safety, Pharmacokinetics, and Pharmacodynamics of BIIB054 in Participants With Parkinson's Disease	Drug: Placebo   Drug: BIIB054	Biogen	Phase 2	Intervention	Research Site, La Jolla, California, Research Center of Southern California, Oceanside, California	<a href="https://clinicaltrials.gov/show/NCT03318523">https://clinicaltrials.gov/show/NCT03318523</a>
An Open-Label Phase 3 Study to Examine the Long-Term Safety, Tolerability and Efficacy of AP-130277 for the Acute Treatment of "Off" Episodes in Patients With Parkinson's Disease	Drug: AP-130277	Sunovion	Phase 3	Intervention	Research Center of Southern California, Oceanside, California	<a href="https://clinicaltrials.gov/show/NCT02542696">https://clinicaltrials.gov/show/NCT02542696</a>

Thanks to Pete Fronte, Altura, for providing this information.

This matrix is intentionally printed sideways. And yes, the type is very small! Please review the full document on our website.  
Interested in checking out one of the studies? Copy the URL (right column) into your web browser.

Our continuing thanks to the  
Neurology Center of Southern California  
for our Newsletter postage.



Serving San Diego County with four locations:  
Carlsbad, Escondido, Poway, La Jolla  
760-631-3000